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The impact of psychiatric disorders on caregivers: An integrative predictive model of burden, stigma, and well-being

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Abstract

Purpose: The study investigates the predictors of caregivers' experienced burden, stigma, and well-being, when looking after family members diagnosed with a psychiatric disorder. **Design and Methods:** This cross-sectional study included 168 caregivers; perceived burden, stigma, well-being, knowledge, illness perception, and medical variables were assessed.

Findings: A number of correlates of burden, stigma, and well-being have been identified and are being discussed. The integrative predictive model showed that the caregiver's emotional representation of illness best predicts burden (β = 0.38, p < 0.001), stigma (β = 0.53, p < 0.001) and well-being (β = -0.36, p < 0.001).

Practice Implications: Our results can enable health professionals to tailor psychosocial interventions addressed to family members of individuals living with a psychiatric condition.

KEYWORDS

burden, caregivers, emotional representation, genetic counselling, stigma, well-being

1 | INTRODUCTION

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Looking after a family member diagnosed with a psychiatric condition, especially for those who become main caregivers, is a complex task as it involves providing dedicated and often demanding or challenging assistance and support, as well as often having several practical responsibilities (e.g., informational, logistic, financial, etc.) (Clibbens et al., 2019; Dwyer et al., 1994; Gérain & Zech, 2019).

Caregivers are exposed to high levels of stress (Adelman et al., 2014; Caicedo, 2014; Gérain & Zech, 2019; Sołtys & Tyburski, 2020) and many

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report feelings of social isolation, stigma, grief, shame, guilt, anger, and helplessness (Clibbens et al., 2019; Tyo & McCurry, 2020). Besides this, additional challenges are brought on by unpredictable and problematic behaviors associated with the illness (e.g., hyperactivity, aggression, self-destructive behaviors) (Higgins et al., 2005; Oruche et al., 2012). Regardless of the age of the patient (e.g., children, adolescents, or adults), the caregiver role is associated with feelings of burden, health-related difficulties, and lower well-being (Baker et al., 2011; Bom et al., 2018; Estes et al., 2009).

Caregiver burden (Gérain & Zech, 2019; Liu et al., 2020; Sołtys & Tyburski, 2020; Tsai et al., 2021) is a concept that refers to the physical, emotional, and mental exhaustion or depersonalization a caregiver can experience (Gérain & Zech, 2019; Thompson et al., 2014) and it has been shown to have a negative impact on both the caregiver and the patient (Oruche et al., 2012). Caregivers' gender (i.e., female), educational level, professional status, financial difficulties, number of hours spent caregiving, and other psychosocial aspects (e.g., depression and anxiety levels, coping mechanisms, social isolation, etc.), all influence the level of burden experienced (Adelman et al., 2014; Gérain & Zech, 2019). Some of these risk factors (e.g., gender, marital status, mental health status, etc.) are also known to influence caregivers' well-being (Chappell et al., 2014) which in turn impacts the patients' well-being and overall recovery (Schulz & Sherwood, 2008).

The literature has predominantly focused on the impact chronic conditions (e.g., Down syndrome, autism, sickle cell disease, dementia, Alzheimer's disease, cancer, stroke) can have on caregivers, especially in terms of burden, quality of life, and well-being (Adelman et al., 2014; Barros et al., 2017; Carden et al., 2016; Jeyagurunathan et al., 2017; Macedo et al., 2015: Sheng et al., 2018). Recently, other variables such as illness perception or stigma about mental health have become topical (Han et al., 2021; Hinshaw, 2005; Zhang et al., 2018). For example, parents of children diagnosed with a psychiatric disorder have been reported to have a tendency to blame themselves for their child's condition (Hasson-Ohayon et al., 2019). More so, they appear to incorporate stigmatizing attitudes and knowledge about the disorder in their general representation of the condition (Hasson-Ohayon et al., 2019; Moses, 2010; Zhang et al., 2018), which can have an impact on the child's health outcomes (Hasson-Ohayon et al., 2019; Moses, 2010). Previous evidence has also shown illness perception impacts patients' adherence to treatment (Bassi et al., 2015), caregivers' coping strategies (Al Anbar et al., 2010; Bassi et al., 2015), as well as the well-being, anxiety, and depression for both patients and caregivers (Bassi et al., 2015).

We believe this study can help tailor future psychosocial interventions for family members of patients with psychiatric conditions. We know from previous research that psychiatric genetic counseling can improve knowledge (Hippman et al., 2016), reduce stigma (Costain et al., 2012a, 2012b), and increase empowerment and self-efficacy (Austin, 2019; Inglis et al., 2014; Semaka & Austin, 2019) in patients living with psychiatric conditions. Recent studies have focused on tailoring psychiatric genetic counseling for parents of children with psychiatric conditions (Griesi-Oliveira & Sertié, 2017;

Haakonsen Smith et al., 2017; Hoang et al., 2018). These psychosocial interventions, among others (e.g., cognitive-behavioral therapy, mindfulness-based interventions, stress-management programs, etc.), are undoubtedly a promising option for families as they are aimed to specifically target understanding and adaptation to conditions with familial implications (Resta et al., 2006).

Given the complex nature of the caregiver's role and the impact it has been shown to have on the emotional, psychological, and physical health of both patients and caregivers (Bom et al., 2018; Jeyagurunathan et al., 2017; Revenson et al., 2016), we aimed to investigate the main predictors of caregiver's experienced burden, stigma, and well-being when looking after family members diagnosed with a psychiatric disorder.

2 | METHOD

2.1 | Participants and procedure

Family members of individuals diagnosed with a psychiatric condition were invited to participate in this study, between May 2017 and November 2019. Participants had to be the main caregivers (e.g., spouses, parents, grandparents, legal guardians) of an adult or young person diagnosed with a psychiatric condition and were included only if they had constant contact with the patient (e.g., lived in the same home; looked after the patient daily). All family members were invited to participate, on a voluntary basis, from either the Pediatric or the Adult Psychiatry Clinics from the Cluj-Napoca County Hospital, which is the second-largest hospital in Romania. The caregivers of adult patients reported their family members were diagnosed (as per DSM-V) with schizophrenia, bipolar disorder, schizoaffective disorder, depressive disorder, or alcohol use disorder. The caregivers of children and adolescents mentioned diagnoses (as per DSM-V) such as neurodevelopmental disorders (autism spectrum disorders, attention-deficit and hyperactivity disorder (ADHD), intellectual disabilities), depressive disorders, anxiety disorders, and psychotic disorders. Details about participants' demographics are shown in Table 1. Family members were invited to share their experience as caregivers of a person living with a psychiatric condition. They were informed on the purpose and procedure of the research, received the questionnaire in a paper-pencil format, and returned it completed at the next appointment. The study was carried out in accordance with the ethical standards of the Babes-Bolyai University institutional research board. Written informed consent was obtained from all individuals participating in this study.

2.2 | MEASURES

2.2.1 | The demographic questionnaire

It included 18 questions about participant's gender, age, marital status, number of children, education, professional status, living

TABLE 1 Demographics

Variable	n (%)	m (SD)
Gender		
Female	132 (78.6)	
Male	36 (21.4)	
Ethnicity		
Romanian	147 (87.5)	
Hungarian	16 (9.5)	
Other	5 (3)	
Urban	119 (70.83)	
Rural	49 (29.17)	
Less than high school	51 (30.35)	
Highschool	64 (38.09)	
Higher education	53 (31.54)	
Married/serious relationship	120 (71.3)	
Widow	13 (7.8)	
Divorced/separated	17 (10.2)	
Never married	7 (4.2)	
Single	11 (6.5)	
Occupational status		
Student	9 (5.4)	
Unemployed	30 (17.8)	
Employed	100 (59.5)	
Retired	29 (17.3)	
Relationship to patient		
Parent	75 (44.6)	
Sibling	18 (10.7)	
Partner	31 (18.5)	
Child	23 (13.7)	
Cousin	3 (1.8)	
In law	5 (3.0)	
Grandparent	5 (3.0)	
Other	8 (4.8)	
Diagnostic of patient		

Diagnostic of patient

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Adult patients	
Schizophrenia	27 (16.1)
Bipolar disorder	7 (4.2)
Schizoaffective disorder	1 (0.6)
Depression	31 (18.5)
Alcohol addiction	32 (19.0)
Pediatric patients	

TABLE 1 (Continued)

Variable	n (%)	m (SD)
Autism spectrum disorders	20 (12.0)	
ADHD	26 (15.6)	
Depression	5 (3.0)	
Bipolar disorder	2 (1.2)	
Anxiety disorders	6 (3.6)	
Psychotic disorders	3 (1.8)	
Intellectual disabilities	8 (4.8)	
Age		47.71 (13.18)
Number of children		1.65 (1.01)

Note: N = 168

Abbreviations: ADHD, attention-deficit and hyperactivity disorder;m,

means: SD. standard deviation.

environment, religion, relationship with the patient, diagnosis of the patient, time of diagnosis, and number of times the patient has been hospitalized.

2.2.2 | Involvement Evaluation Questionnaire (IEQ; van Wijngaarden et al., 2000)

It is designed to measure levels of burden and distress among family carers of people with a severe mental illness. IEQ has 31 items on a five-point Likert scale (never, sometimes, regularly, often, and always) looking at (1) tension between family members and the patient (nine items); (2) supervising and supporting the patient's condition on a daily basis (e.g., sleep, medicine intake, etc.) (six items); (3) worrying about the safety and future of the patient (six items); and (4) urging the patient by motivating, activating and stimulating him/her toward self-care (eight items). The internal consistency of the scale varies for the four subscales from 0.68 to 0.86, with 0.87 to 0.91 for the sum score and a high test-retest reliability (van Wijngaarden et al., 2000).

2.2.3 | Self-Stigma in Relatives of People with Mental Illness Scale (SSRMI; Morris et al., 2018)

It is a 30-item scale that measures self/internalized stigma among family members of individuals with a psychiatric diagnosis. Each statement can be answered on a five-point Likert scale, from 1 = strongly disagree to 5 = strongly agree. The internal consistency is α = 0.90, and the test-retest reliability as well as the construct reliability were also found adequate. Factor analysis was performed and concluded one single factor explained 29.57% of the variance, with 26 of the total 30 items having significant loadings on the factor (Morris et al., 2018).

2.2.4 | The Psychological General Well-Being Index (PGWBI; Dupuy, 1990; Grossi & Compare, 2014)

It is a 22-item scale that measures subjective psychological well-being. It has six subscales: anxiety, depression, positive well-being, self-control, general health, and vitality (Grossi & Compare, 2014). Response options are on a six-point Likert scale, with answers capturing the frequency or intensity of the constructs investigated. The maximum score is 110 and it represents the highest level of well-being. Scores can be placed in one of three categories: being positive (scores between 73 and 110), moderate psychological distress (scores between 61 and 72), and severe psychological distress (scores between 0 and 60). Internal consistency of PGWBI varies from 0.90 to 0.94, with test-retest reliability of around 0.80 (Grossi & Compare, 2014).

2.2.5 | Knowledge (Costain et al., 2012a)

It was measured using a 24-item questionnaire designed to assess the level of knowledge caregivers have about their family member's psychiatric diagnosis. All questions were adapted to the purpose of the study. Participants could respond with true, false, or do not know to questions about potential causes, genetic and environmental factors, medication, and other related topics about mental illnesses. The internal consistency of the questionnaire is 0.80 (Costain et al., 2012a).

2.2.6 | Illness Perception Questionnaire: Relatives' Version (IPQS-Relatives; Lobban et al., 2005)

It is an adapted version of the IPQS-relatives, which was originally designed for schizophrenia. The original wording was adapted for the purpose of this study to reflect the parent-child relationship (e.g., this questionnaire aims to assess how you perceive your child's mental health problem). IPQ-relatives has the following subscales: identity (58 items), cause (26 items), timeline-acute/chronic (6 items), timeline-cyclical (4 items), consequences for the patient (11 items), consequences for the relative (9 items), personal control-patient (4 items), personal control—relative (4 items), personal blame—patient (3 items), personal blame—relative (3 items), treatment control/cure (5 items), illness coherence (5 items), emotional representation (9 items). Each item can be rated on a five-point Likert scale, from 1 = strongly disagree to 5 = strongly agree. The internal consistencies of the subscales vary from 0.63 to 0.83, with the exception of one subscale, the personal blame-relative subscale which has an internal consistency of 0.43 (Lobban et al., 2005).

2.3 | Data analysis

Data collected in this cross-sectional study was analyzed to explore the main predictors of caregivers' experienced burden, stigma, and well-being. In the first phase, the descriptive statistics and correlation analyses for all variables included were computed. In a second phase, to explore the best predictors of the investigated variables, three predictive models were computed using linear regression analysis. Data were analyzed using IBM SPSS Statistics for Windows, v.26 software.

3 | RESULTS

3.1 | Demographics

A total of 168 participants took part in this study, 98 of which were caregivers of adult patients and 70 of which were caregivers of children and adolescents with psychiatric disorders. In total, participants were caregivers of patients with depression (21.5%), alcohol use disorder (19%), psychotic disorders (17.9%), ADHD (15.6%), autism spectrum disorders (12%), bipolar disorder (5.4%), intellectual disabilities (4.8%), anxiety disorders (3.6%), and schizoaffective disorder (0.2%). Details about the participants' demographics are included in Table 1.

3.2 | CORRELATION ANALYSES

3.2.1 | Sociodemographic correlates of burden, stigma, and well-being

The matrix correlation showing the relationship between burden, stigma, well-being and the sociodemographic variables is shown in Table 2. Of all demographic variables, age and gender are most informative. Age was positively associated with burden (r = 0.193, p < 0.05) and gender was positively associated with both burden (r = 0.206, p < 0.05) and stigma (r = 0.199, p < 0.05). Table 3

We also looked at the correlation between burden, stigma, well-being, and family relationship. Our data show that having a parent with a psychiatric condition is positively associated with the burden (r = 0.188, p < 0.05), while being the partner of someone with a psychiatric diagnosis is positively associated with stigma (r = 0.273, p < 0.01) and negatively associated with well-being (r = -0.159, p < 0.05). Interestingly, being a parent of a patient with a psychiatric condition is negatively associated with stigma (r = -0.167, p < 0.05) (Table 4).

3.2.2 | Medical correlates of burden, stigma, and well-being

We then explored the correlation between medical variables (e.g., diagnosis and hospital experience) and burden, stigma, and wellbeing. Our data show that a diagnosis of alcohol use disorder is positively associated with caregivers' burden (r = 0.167, p < 0.05) and stigma (r = 0.227, p < 0.01). With the exception of adult schizophrenia

TABLE 2 The matrix correlation for the relationship between burden, stigma, well-being, and sociodemographic variables

	1	2	3	4	5	6	7	8
1. Burden	-							
2. Stigma	0.434**	-						
3. Well-being	-0.299**	-0.215**	-					
4. Age	0.193*	0.113	-0.095	-				
5. Gender (0 = male, 1 = female) ^a	0.206*	0.199*	-0.027	-0.010	-			
6. Number of children	0.027	0.029	0.107	0.321**	0.195*	-		
7. Income	-0.044	0.009	-0.025	0.039	0.056	-0.042	-	
8. Education ^b	-0.018	0.026	0.039	-0.015	0.101	-0.256**	0.137	-
9. Residence (0 = urban, 1 = rural) ^a	0.074	0.108	0.015	-0.141	-0.022	0.209**	-0.053	-0.301**

Note: N = 168.

TABLE 3 The matrix correlation for the relationship between burden, stigma, well-being, and family relationship

	1	2	3	4	5	6
1. Burden	-					
2. Stigma	0.434**	-				
3. Well-being	-0.299**	-0.215**	-			
4. Child ^a (1 = child, 0 = other)	0.188*	0.098	-0.068	-		
5. Life partner (1 = life partner, 0 = other) ^a	0.109	0.273**	-0.159*	-0.189*	-	
6. Brother/sister (1 = brother/sister, 0 = other) ^a	-0.051	-0.042	-0.103	-0.138	-0.165*	-
7. Parent (1 = parent, 0 = other) ^a	-0.120	-0.167*	0.154	-0.358**	-0.427**	-0.311**

Note: N = 168.

TABLE 4 Medical correlates of burden, stigma, and well-being (diagnosis variables and hospital experience)

	1	2	3	4	5	6	7	8
1. Burden	-							
2. Stigma	0.434**	-						
3. Well-being	-0.299**	-0.215**	-					
4. Number of hospitalizations	-0.045	0.062	0.037	-				
5. Time since diagnosis	-0.101	-0.015	-0.005	-0.112	-			
6. Adult schizophrenia ^a	-0.150	-0.075	0.035	0.344**	-0.016	-		
7. Adult depression ^a	-0.050	-0.085	-0.054	-0.010	0.056	-0.208**	-	
8. Alcoholism ^a	0.167*	0.227**	-0.101	-0.055	0.002	-0.212**	-0.231**	-
9. Pediatric diagnosis ^a	0.061	-0.027	0.124	-0.240**	-0.033	-0.370**	-0.402**	-0.410**

Note: N = 168.

^{*}p < 0.05.

^{**}p < 0.01.

^aBiserial correlations.

^bSpearman correlations.

^{*}p < 0.05.

^{**}p < 0.01.

^aBiserial correlations.

^{*}p < 0.05.

^{**}p < 0.01.

^aBiserial correlations.

correlating with a higher number of hospital admissions (r = 0.344, p < 0.01), no other statistically significant correlations were found between the medical variables and burden, stigma, and well-being.

3.2.3 | Cognitive correlates of burden, stigma, and well-being

We further explored the cognitive (i.e., knowledge and illness perception) correlates of burden, stigma, and well-being. The statistical analysis showed knowledge was negatively correlated with stigma (r = -0.258, p < 0.01) and positively correlated with well-being (r = 0.166, p < 0.05). For illness perception, correlations were computed for each component of the IPQ scale (i.e., acute/chronic timeline, consequences for the patient, consequences for the relative, personal blame of the patient, personal blame of the relative, illness coherence, emotional representation, etc.). Of all the IPQ subscales, the most significant correlates of burden, stigma, and well-being were the consequences for the relatives and the emotional representation of the condition. The consequences for the relatives subscale correlates positively with the burden (r = 0.447, p < 0.01) and stigma (r = 0.538, p < 0.01) and negatively with well-being (r = -0.306, p < 0.01)p < 0.01). The emotional representation subscale is positively correlated with both burden (r = 0.0.430, p < 0.01) and stigma (r = 0.597, p < 0.01) and negatively with well-being (r = -0.383, p < 0.01)p < 0.01). For more details see Table 5.

3.3 | An integrative predictive model of burden

To select the relevant predictors of the burden from each category of correlates (i.e., sociodemographic/familial, medical, and cognitive), we tested inside each category the predictive value of the relevant factors whilst controlling for the rest of them. Our data show that in the sociodemographic/familial category, the significant predictors were age (β = 0.17, p = 0.038) and gender (β = 0.21, p = 0.008). In the medical category, the only significant correlate was alcohol use disorder (β = 0.16,p = 0.043), and in the cognitive category the only significant predictor is emotional representation (β = 0.26, p = 0.009). Consequently, these predictors were simultaneously introduced into a multiple linear predictive model of burden. Results are presented in Table 6.

The tests performed to verify if the data met the assumption of collinearity indicated that multicollinearity was not a concern, all variance inflation factor (VIF) values being less than 10 and all Tolerance values above 0.1.

Results show that when simultaneously controlling for all relevant factors, the only significant predictors of burden remain gender (β = 0.18, p = 0.015) and the emotional representation of illness (β = 0.38, p < 0.001), indicating that a higher negative representation of the condition predicts a higher level of burden, particularly in women.

3.4 | An integrative predictive model of stigma

As in the case of burden, to select the relevant predictors of stigma from each category of correlates (sociodemographic/familial, medical, and cognitive), we tested for each category the predictive value of the relevant factors whilst controlling for the rest of them. The results show that in the sociodemographic/familial category, the significant predictors were gender (β = 0.18, p = 0.016) and the life partner status (β = 0.22, p = 0.008). In the medical category, the only significant correlate was alcohol use disorder (β = 0.22, p = 0.004), and in the cognitive category, the significant predictor is emotional representation (β = 0.40,p < 0.001). Consequently, these predictors were simultaneously introduced into a multiple linear predictive models of stigma. Results are presented in Table 7.

The tests performed to verify if the data met the assumption of collinearity indicated that multicollinearity was not a concern, with all VIF values being less than 10 and all Tolerance values above 0.1.

As results show, when simultaneously controlling for all relevant factors, the only significant predictor of stigma remains the emotional representation of illness (β = 0.53, p < 0.001), which shows that a higher negative representation of the condition predicts a higher level of stigma.

3.5 An integrative predictive model of well-being

Finally, to select the relevant predictors of well-being from each category of correlates (sociodemographic/familial, medical, and cognitive), we tested the predictive value of the relevant factors whilst controlling for the rest of them. Our results showed that in the sociodemographic/familial category, the only significant predictor was the life partner status (β = -0.16, p = 0.045). In the medical category, none of the variables had a significant predictive value, while in the cognitive category the only significant predictor is the emotional representation (β =-0.32, p = 0.005). Consequently, these predictors were simultaneously introduced into a multiple linear predictive model of well-being. Results are presented in Table 8.

The tests performed to verify if the data met the assumption of collinearity indicated that multicollinearity was not a concern, all VIF values being less than 10 and all Tolerance values above 0.1.

Our results show that when introducing the most relevant predictors of well-being into an integrative model, the only significant predictor remains the emotional representation of illness (β =-0.36, p < 0.001). This indicates that a less negative representation of the condition predicts a higher level of well-being.

4 | DISCUSSION

Our main aim was to identify the main predictors of caregivers' experienced burden, stigma, and well-being when looking after family members diagnosed with a psychiatric disorder.

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TABLE 5 Cognitive correlates of burden, stigma, and well-being	of burden,	stigma, an	ոժ well-bein	₽ 0												
	7	2	ო	4	5	2 9	7 8	6		10	11	12 1	13	14 15	16	
1. Burden																
2. Stigma	0.434**	1														
3. Well-being	-0.299**	-0.215**	ı													
4. Knowledge	-0.129	-0.258**	0.166*	ı												
5. IPQ-identity	0.285**	0.154	-0.134	0.136	1											
6. IPQ-cause	0.159	0.272**	-0.183*	-0.196*	0.423**											
7. IPQ- timeline acute/chronic	0.288**	0.280**	-0.128	-0.052	0.338**	0.204* -										
8. IPQ-timeline cyclical	0.261**	0.188*	-0.116	0.045	0.405**	0.191*	0.715** -									
9. IPQ-consequences patient	0.425**	0.346**	-0.218**	0.100	0.455**	0.296**	0.621**	0.531** -								
10. IPQ-consequences relative	0.447**	0.538*	-0.306**	-0.130	0.200*	0.259**	0.471**	0.332**	0.627** -							
11. IPQ- Personal control patient	-0.029	-0.124	-0.049	-0.302**	0.312** 0.115		0.111	0.197*	0.200*	0.053						
12. IPQ-personal control relative	0.139	990.0	-0.041	0.188*	0.096	-0.126	0.275**	0.294**	0.183*	0.219**	0.333**					
13. IPQ-personal blame-patient	0.265**	0.216**	-0.167*	-0.142	0.100	0.218**	0.153	0.190*	0.293** 0.337**	0.337**	0.282**	0.134				
14. IPQ-personal blame-relative	960.0	060.	-0.130	-0.207**	-0.135	-0.009	-0.049	0.059 -0.033		980.0	0.084	0.282** 0.469**	469**			
15. IPQ-treatment control/cure	-0.019	-0.007	0.094	0.139	0.116	-0.141	0.031	0.186* -0.019		-0.044	0.145	0.058	0.075	-0.071 -		
16. IPQ-illness coherence	-0.021	0.204*	-0.155	-0.532**	-0.123	0.224** -0.044		-0.085	-0.102	0.094	-0.182*	-0.072 C	0.099	0.200** -0.335**	335** -	
17. IPQ-emotional representation	0.430**	0.597**	-0.383**	-0.231**	0.133	0.252**	0.307**	0.274**	0.404**	0.685** -0.067	-0.067	0.105	0.282**	0.202** 0.	0.041 0.301**	*
Note: N = 168.																

Abbreviation: IPQ, Illness Perception Questionnaire for schizophrenia: relatives' version.

 $^*p < 0.05$. $^{**}p < 0.01$.

TABLE 6 The integrative predictive model of burden (the most relevant sociodemographic, medical and cognitive factors)

Variables	В	SE	β	t	р
(Constant)	27.109	9.037		3.00	0.003
Age	0.157	0.110	0.108	1.42	0.156
Gender (0 = male, 1 = female)	8.759	3.568	0.185	2.45	0.015
Alcoholism (1 = alcoholism, 0 = other)	3.368	3.619	0.071	0.93	0.354
IPQ-emotional representation	1.074	0.219	0.385	4.90	0.000

Note: F(4, 168) = 11.16, p < 0.001, $R^2 = 0.25$.

TABLE 7 The integrative predictive model of stigma (the most relevant sociodemographic, medical and cognitive factors)

Variables	В	SE	β	t	р
(Constant)	27.155	5.988		4.535	0.000
Gender (0 = male, 1 = female)	4.809	2.682	0.117	1.793	0.075
Life partner-status	3.443	2.874	0.083	1.198	0.233
Alcoholism (1 = alcoholism, 0 = other)	3.737	2.780	0.091	1.345	0.181
IPQ-emotional representation	1.273	0.164	0.536	7.779	0.000

Note: F(4, 168) = 23.23, p < 0.001, $R^2 = 0.38$.

The caregivers in our study were predominantly female, with an average age of 48 years old, living in urban areas, married, and employed. Most patients had been diagnosed with depression, bipolar disorder, anxiety disorders, alcohol use disorder, psychotic disorders, ADHD, and autism spectrum disorders and were looked after by parents, partners, or children. Similar to other studies (Adelman et al., 2014; Chappell et al., 2014; Tsai et al., 2021), our data showed that caregivers' gender was positively associated with burden and stigma, with women feeling more burdened and stigmatized than men. Also, having a parent with a psychiatric disorder was associated with burden, but not with stigma and wellbeing, while having a partner with a psychiatric disorder was mainly associated with stigma and lower well-being, but not with the burden. Our results also show that having a child with a psychiatric disorder was negatively associated with stigma. This finding is particularly interesting given the relatively small number of studies exploring parents' stigma (Han et al., 2021; Hinshaw, 2005; Zhang et al., 2018), with most studies focusing on parents' well-being, burden, and quality of life (Adelman et al., 2014; Jeyagurunathan et al., 2017; Macedo et al., 2015; Oruche et al., 2012; Sheng et al., 2018). One potential interpretation is that, as in the case of well-being (Hammersmith & Lin, 2016), stigma might be experienced differently by caregivers of adult versus pediatric patients. A recent study looking at caregivers of young mental health patients from Singapore

TABLE 8 The integrative predictive model of well-being (the most relevant sociodemographic and cognitive factors)

Variables	В	SE	β	t	р
(Constant)	94.194	3.579		26.317	0.000
Life partner-status	-1.724	2.383	-0.057	-0.723	0.471
IPQ-emotional representation	-0.632	0.136	-0.365	-4.652	0.000

Note: F(2, 168) = 13.34, p < 0.001, $R^2 = 0.14$.

showed parents felt more stigmatized than sibling or spouse caregivers (Zhang et al., 2018). In the case of well-being, the explanations for the identified differences may be associated with various demographic and socioeconomic factors (e.g., gender, age, race, marital status, work status, health status etc.), the specific time point in a person's life course when well-being was measured, as well as the measurements used (Hammersmith & Lin, 2016). For both stigma and well-being, the identified differences between adult and pediatric caregivers clearly need further exploration.

As expected, the burden was associated with stigma, and wellbeing was negatively correlated with both burden and stigma. We then explored in detail the main correlates and predictors of burden, stigma, and well-being. The statistical analysis showed caregivers' knowledge about their family member's psychiatric condition impacts the level of stigma and well-being experienced, but not the burden. Additionally, the perceived consequences for the relative and the emotional representation of the relatives' condition were both found to be positively associated with burden and stigma and negatively associated with wellbeing. Illness representation has been a growing topic of interest in the field of mental health, but mostly from the perspective of patients (Averous et al., 2020). For patients, perceptions of controllability, the sense of coherence, and the negative consequences of the illness were previously associated with greater chances of seeking help and actively engaging in coping strategies (Baines & Wittkowski, 2012). Nonetheless, these representations influence not only the way patients cope with their psychiatric condition (Baines & Wittkowski, 2012), but they appear to impact caregivers as well (Hasson-Ohayon et al., 2019). Studies from Canada, the United States, and Australia showed that parents' illness perception of controllability, consequences, illness coherence, and emotional representations are associated with problem severity, psychological adjustment, and treatment accessibility (Shanley & Reid, 2015); parents' and adolescent' perceptions of illness controllability is associated with self-stigma (Moses, 2010); and parents' illness perception (specifical attribution of control) impacts the level of criticism they express toward the young people with psychosis (McNab et al., 2007). Our findings contribute to existing empirical data with evidence showing that illness perception can also impact caregivers' burden and stigma.

The main predictors of caregivers' burden previously investigated have focused on financial difficulties, interpersonal relationships, concerns about treatment, and patients engaging in risk or harming behaviors (e.g., drinking, self-harm, taking drugs) (Stomski and

Morrison, 2019). Other studies showed that a low sense of comprehensibility and self-efficacy (Sołtys & Tyburski, 2020), perceived stigma, and high levels of distress (Rafiq & Sadiq, 2019) can impact caregivers' mental health. Our findings complement previous studies by showing that the emotional representation of the psychiatric condition is a strong predictor of caregivers' burden. Caregivers' emotional representation of a patient's psychiatric condition plays a key role not only for their mental health but also for their adaptation to the condition (Baines & Wittkowski, 2012; Bassi et al., 2015).

This study is not without its limitations. The sample size is relatively small, therefore results should be interpreted with caution. Also, of note, our sample is primarily comprised of female participants; this was due to the fact that most caregivers who accompanied patients to the appointments in the Pediatric or the Adult Psychiatry Clinics were female, and this is where the recruitment was organized. Future studies should consider a more gender-balanced sample.

In sum, we can reliably conclude that the caregivers' emotional representation of the patients' psychiatric condition is the strongest predictor of their burden, stigma, and well-being. To better understand the caregivers' experience, how to best support them, and how to better address the difficulties they encounter, future research needs to investigate the impact illness perception has on these variables. Psychiatric genetic counseling is a valuable and effective psychosocial intervention that may help tackle and manage these issues, with benefits for both patients and family members.

4.1 | Implications for psychiatric nursing practice

Psychiatric conditions impact both patients and their caregivers. Looking after someone with mental health difficulties can be challenging; clearly, the experienced burden or stigma can add more pressure on this complex role. Our results show that illness perception (specifically, the emotional representation of the patients' condition) can impact caregivers' burden, stigma, and well-being. As our study has focused on informal caregivers, it is important that future studies explore if these results are also applicable to formal caregivers (e.g., mental health nurses), who often share similar roles as informal caregivers, as well as additional responsibilities. Mental health nurses are mainly trained to work with patients and their efforts are primarily focused on their care and well-being (Hurley et al., 2020; Lakeman et al., 2020; Sampaio et al., 2015). Our study shows that the impact of the diagnosis on family members can be rather complex and profound; nursing practices could consider delivering psychosocial interventions (e.g., support group interventions, skills training, etc.) to support family members of individuals living with a psychiatric condition.

AUTHOR CONTRIBUTIONS

All authors contributed to the study conception and design, material preparation, data collection, and analysis. The first draft of the manuscript was written by Mădălina Radu and all authors commented

on previous versions of the manuscript. All authors read and approved the final manuscript.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

This study was performed in accordance with the Declaration of Helsinki. This study was approved by Babeş-Bolyai University institutional research board. All adult participants were over 18 years old and provided written informed consent to participate in this study.

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